

# After the Psychoeducational Intervention: Turkish Breast Cancer Survivors' Experiences

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## ABSTRACT

**Objective:** To explore breast cancer survivors' life experiences and perceptions about participating in a psychoeducational intervention that aimed at reducing psychological distress and in improvement of the quality of life.

**Materials and Methods:** This study was a post-trial qualitative descriptive study. Data were collected at semi-structured interviews three months after the psychoeducational intervention. Interviews were conducted with 32 Turkish breast cancer survivors. Obtained data were analyzed with inductive content analysis.

**Results:** The data were categorized into three themes: personal growth, unmet needs and recommendations about the quality of the psychoeducation. Survivors explained that they had positive changes in their self-concept, view of life and relationships after the psychoeducational intervention. In addition, they mentioned the unmet needs to join support groups and raise public awareness to decrease stigma over breast cancer patients in the society.

**Conclusion:** The results of the present study provide new insights into experiences of breast cancer survivors who participated a psychoeducational intervention and provide guidance for attempts to improve survivorship care via psychoeducation to professionals. Psychoeducational interventions should be continuously offered to provide psychosocial support for breast cancer survivors. Future research into psychoeducation for breast cancer survivors should be restructured to involve social support.

**Keywords:** Breast cancer, survivors, psycho-education, qualitative research

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## Introduction

The number of breast cancer survivors has increased worldwide. The five-year relative survival rate for breast cancer patients has risen to 89% (1). Despite improvements in the survival rates, the post-treatment period for breast cancer is a process of restructuring and adjustment. Many studies have shown that breast cancer survivors may have persistent physical, and psychosocial problems (2-5). Systematic review and meta-analyses also underline the necessity to offer psychoeducational interventions to help breast cancer survivors manage their biopsychosocial problems and improve their emotional wellbeing and the quality of their life (6, 7).

Despite their reported benefits, there have been few studies using post-treatment psychoeducational interventions for breast cancer survivors. The aim of those studies was to test effects of the psychoeducation on the quality of life and psychological distress (8, 9). In a randomized controlled study, a post-treatment psychoeducational intervention reduced anxiety, depression, anger and fatigue and improved interpersonal relationships and several subscales of the quality of life; general health status, emotional wellbeing and role performance (10). In a comparative study, a psychoeducational program was found to offer a higher quality of life and emotional well-being and lower distress than conventional care (11). In another study, psychoeducation provided improvement in knowledge and preparedness for life after treatment compared to routine care (12). Abovementioned studies mostly evaluated effects of psychoeducation based on data collected with scales and could not supply comprehensive data. The aim of this study was to explore breast cancer survivors' experiences and perceptions about participating in a home-based psychoeducational intervention. Results of an experimental study showed that a home-based psychoeducational intervention was effective in reduction of psychological distress and in improvement of the quality of life in breast cancer survivors (13). However, exploring experiences qualitatively can provide more comprehensive understanding of the experiences of survivors who participate in psychoeducation. Such research allows an examination

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of psychoeducation from different perspectives and barriers to taking advantage of it and conducting it. In addition, exploring how breast cancer survivors perceive such interventions, and what they have experienced will provide guidance in developing interventions which are effective in improving adjustment in the post-treatment period.

## Materials and Methods

### Study design and participants

This was a qualitative descriptive study. In a qualitative descriptive approach, experience is defined from the perspective of the person, and a comprehensive summary of experience is offered (14). The criterion for sampling was to attend all the psychoeducation sessions. Therefore, all records of attendance in the psychoeducation were examined. The survivors who attended all the psychoeducation sessions were invited to take part in the study and they were explained the nature and purpose of this qualitative study. Participation was on a voluntary basis. All the survivors (n=32) agreed to participate. The average age of the survivors was 53.71 years, and most were secondary school graduates (37.5%), married (84.4%), and unemployed (84.4%). The majority of the survivors (62.5%) had stage II breast cancer. Time to complete hospital-based treatment ranged between 3 months and 24 months with a mean period of 12.09 months.

### Data collection

Data were collected through semi-structured interviews by a researcher educated and experienced in psycho-oncology, breast cancer and qualitative studies in the participants' homes. Interviews were conducted at three months following the survivor's participation in the psychoeducational intervention study. Two forms prepared by the researchers were used to collect data. The first was a personal information form that included sociodemographic and clinical characteristics. The second form was a semi-structured interview form that included interview questions. The interviews included the following open-ended questions: What changes have you experienced in your life after the psychoeducation? What do you think about the psychoeducation you received? Interviews were conducted in a quiet and comfortable room in the survivors' homes. Although data saturation was reached at the fifteenth interview, the researcher interviewed all the voluntary participants. Each interview took 20–35 minutes and was audio-recorded.

### Psychoeducational intervention

The psychoeducational intervention was a personalized intervention developed for the Turkish breast cancer survivors (13). The intervention involved four sessions, each of which lasted for 60-90 min, and was offered at the participants' homes. In the first session, the survivors' major problem was determined. Following assessment, psychoeducation focusing on the major problem was offered. At each session, exercises directed towards the participants' major problems, videos and written material were used. In addition, at each session, the survivors' questions about the posttreatment period were answered. At the end of each session, the counsellor and the participants gave feedback to each other and the following session was scheduled. The survivors accessed information they needed as well as guidance for coping with stressors in a psychoeducation booklet. The booklet was created by the researchers in the light of the relevant literature and Turkish breast cancer survivors' needs (2). It included information about changes experienced in the post-treatment period and guidance for overcoming common problems that arose in that period.

### Data analysis

Qualitative content analysis was used to analyze the data. The researcher transcribed verbatim the recorded interviews and the notes taken during the interviews. The transcripts were read several times and they were also compared with the audiotaped interviews to ensure the accuracy of data analysis. Codes likely to arise from each word and each sentence were determined after reading. The codes related to each other were categorized and then themes were defined based on the relevant categories (15). After coding was completed, the researchers discussed the themes and agreed on the findings.

### Rigor of findings

In a qualitative description of data, the strategies of credibility, transferability, dependability, confirmability and application should be considered to ensure the rigor of findings (16). All the researchers are knowledgeable of and experienced with the qualitative method. The interviews were conducted by the same researcher, who noted down her experiences during the interviewing process. Obtained data were analyzed independently by two researchers and the differences between the results were discussed. Then the results were organized and documented by the researchers.

### Ethical considerations

Ethics approval was taken from the Ethics Committee of the Dokuz Eylül University School of Medicine (2011/04-04). The ethical principles adopted were voluntariness, confidentiality and autonomy. All the participants provided their informed consent before the interviews.

## Results

The results showed that psychoeducation supported personal growth but was insufficient to meet some needs. In addition, the survivors made some recommendations about the quality of the psychoeducation. Three main themes were identified: "personal growth", "unmet needs" and "recommendations about the quality of the psychoeducation" (Figure 1).

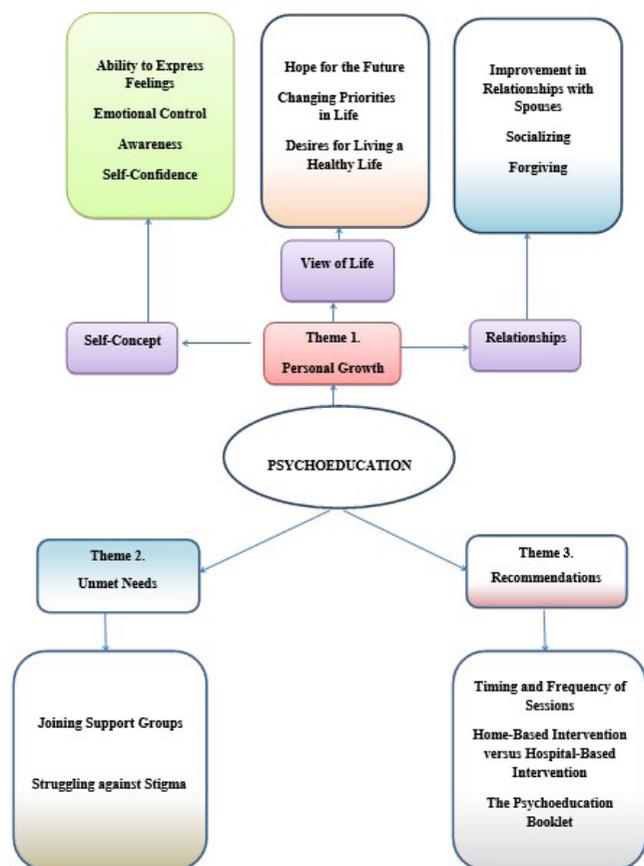
### Theme 1: Personal Growth

The survivors explained that they had changes in their self-concept, view of life and relationships.

#### Self-concept

One contribution of the psychoeducation to self-concept was the ability to express feelings. Interaction with the researcher during the education sessions helped the women to normalize their problems and emotional responses. Especially the women without sufficient social support considered expression of feelings as a positive contribution. *"Sharing is the greatest benefit of the intervention for me. I can talk to you and cry in front of you."* Another contribution of the intervention was to enable women to express their negative feelings more easily. They reported to express such feelings as anger and unhappiness more comfortably after the intervention. *"I didn't use to express my feelings. Now I simply phone or talk about what I think when people make me annoyed."*

Another change in self-concept was to control emotions. A woman offered guidance for anger management reported her experiences as in the following: *"Now I stop and think when I get angry. I don't act angrily, and I try to keep it under control."* The survivors also were reported to contribute to management of fear of recurrence. *"I could learn everything I wondered about. I got worried whenever I had pain because I feared that it might have recurred, but now I know that pain may have many causes."*



**Figure 1** Schematic presentation of the life experiences and feedbacks of breast cancer survivors after the psychoeducation

The women mentioned that they had awareness about their emotions after the psychoeducation. Some women realized that they avoided some feelings creating stress for them before. In fact, the psychoeducation helped them to face their fears. *“I faced my fears and I got rid of them.”* Another field about which the psychoeducation raised awareness in was emotion-cognition interaction. Addressing feelings and questioning irrational cognitions allowed the women to become aware of interactions between their feelings and their cognition. One woman explained positive effects of this awareness on her psychology: *“When one does not have negative thoughts, she/he becomes happier. I feel better. When I had negative thoughts, I used to feel as if I had been ill. Now, I’m aware of it.”* Another dimension with a positive influence on emotional wellbeing of the women was their awareness of their good health. The women used to think as if they had been ill before the psychoeducation. The awareness offered by the intervention enhanced their psychological well-being: *“I used to think I was still ill; I couldn’t get rid of this thought. You made me realize that I wasn’t ill. This made me very happy.”*

The psychoeducation helped the women gain an insight by questioning and recognized what others think about them. It provided the women with a chance of seeing what they had not realized before. *“After the intervention, my view about myself changed. I had opportunities to talk about what characteristics of mine I had to change. I realized what others thought about me.”* Another point the women became aware about was the necessity to do something for themselves: they were alive, and they had to have control over their life. The women said this awareness encouraged them to perform what they had always postponed: *“I realized that I had to do something for myself: I took up a music course which I had postponed for a long time.”*

Some women considered the psychoeducation as an opportunity to reorganize their life and they described an improvement in their self-confidence. They noted that the psychoeducation provided motivation for increased self-confidence and encouraged them to take responsibility. *“I started to do things which I thought I could never do. You gave me the courage to take action.”*

**View of life**

The psychoeducation gave the women a chance of reevaluating their life and questioning their real priorities. *“I had many opportunities to confront my life during the intervention and it continued after the intervention. My view of life and priorities have changed.”*

Another positive effect of the psychoeducation was that it produced hope for the future. The exercises given helped the women to create a connection between the present and the future and have hope for the future. *“I was most influenced by the session during which you made me imagine my old age; it was a turning point for me created by the therapy. I imagined I could get old. I became happy when I could visualize it. I told myself that I could become an old lady; I imagined it, which made me feel good.”* With their feeling of increased hope for the future, the women were more willing to lead a healthy life. *“I established a connection between my present and future lives and I don’t want to have any illnesses from now on. I want to do everything necessary to achieve it. I do sport ... when I get angry with someone, I openly express my anger ...”*

**Relationships**

The women commented that they were more transparent in their relationships with their spouses, which strengthened their relationships. One of the issues which the women had the greatest difficulty in talking to their spouses was their sexual life. They noted that the psychoeducation helped them be more open about such taboo subjects as sexuality and made their relationships stronger. *“We had problems with our sexual life; I hadn’t been able to tell anyone about them. After the intervention, we were able to talk about them more openly. This has made us feel better.”*

Another contribution of the psychoeducation was that it directed women towards socializing more. *“Going out and meeting with friends more made me feel better. My family also realized this change. This has had a positive influence on them, too.”*

The women also told their experiences of forgiving in their relationships. As a result of questioning their life, they preferred to get rid of their negative feelings. Therefore, they acted to replace their attitudes creating an emotional burden in the past with positive ones. *“The best side of the intervention was that I forgave my daughter. I did what I could never do. Now I feel better about this issue.”*

**Theme 2: Unmet Needs**

Some women said that the psychoeducation was insufficient to meet their social needs. They told about their wish for joining support groups and about the necessity to struggle against stigmatization while accessing social support.

**Joining support groups**

Some women reported their need to access support groups. *“We can meet women like us and share our opinions. That would be nice.”*

**Struggling against stigma**

Some women explained that the psychoeducation alone would not be sufficient and would not change negative attitudes of the society

towards cancer. They suggested that cancer-related anti-stigma campaigns should be conducted. *"I believe that people should not talk about diseases much. It forces me to isolate myself. Everybody has a neighbor or a relative with breast cancer. They always tell bad stories about them. Something should be done to make them realize how badly negative stories affect us."*

### **Theme 3: Recommendations about the Quality of the Psychoeducation**

Although the women were satisfied with the quality of the psychoeducation, they made some recommendations about the time, the frequency and the home setting of the psychoeducation and booklet.

#### **Timing and frequency of sessions**

The women recommended that the psychoeducation should start as soon as the diagnosis of cancer is made and should be continued after treatment. *"A good work. If it had started just after diagnosis of cancer, it would be better. I would like the psychoeducation to continue in the future."* Another recommendation was related to the number and the frequency of the sessions. *"I wish the number and the frequency of the sessions were higher."*

#### **Home-based intervention versus hospital-based intervention**

The women were grateful for conduction of the psychoeducation at their home. In fact, a hospital atmosphere was a stressor for the women as it reminded them of their disease. *"I feel relaxed at home. However, I feel stressed out in hospital."*

#### **The psychoeducation booklet**

Another recommendation was related to the concept "survivor" in the booklet. Some women commented that the word survivor had a negative effect on them since it reminded them of cancer and death. Therefore, they recommended replacing the word survivor with a more positive one. *"I didn't like the word survivor. It reminds me of death and cancer... Instead of the word 'survivor', the phrase 'people who say hello to life again' can be used."*

### **Discussion and Conclusion**

The results of this study showed that the psychoeducation improved self-concept, view of life and relationships of the breast cancer survivors. It can be suggested that the psychoeducation supported post-traumatic growth (PTG), which is consistent with the literature (10, 17). PTG can be classified into three main changes; i.e. changes in perception of self, relationships with others and philosophy of life (priorities, appreciation, and spirituality) (18). It is important to explain components of psychoeducation which provoke growth. In a study on long-term breast cancer survivors, PTG was shown to be related to the mental quality of life and happiness (19). Similarly, a decrease in psychological distress is related to PTG (20). In a qualitative study on breast cancer survivors, the feeling of hope and having life goals contributed to PTG (21). In addition, concerning changes in self-concept and relationships, it can be said that psychoeducation potentially facilitates mentalization. Mentalizing refers to understanding and interpreting one's own and others' behavior conjoined with mental states (desires, needs, feelings, thoughts and beliefs) (22, 23). The psychoeducation helped the survivors to make sense of their major problems and recognize their feelings about these problems and thus supported mentalizing these experiences. Psychoeducation enables one to stay in a certain state and understand that state meaningfully and become aware of feelings, which are the targets of many dynamic therapies. At this point, emotional awareness – mentalized affectivity, is impor-

tant for identifying, organizing and expressing feelings (23). A person's awareness of own feelings through mentalizing helps to be open to self and others. This aspect of mentalizing is crucial for establishing positive relationships with oneself and others and having a positive psychological health (24). In this study, it might have contributed to recognition of effects of negative feelings and creation of alternative ways of thinking and reinforced awareness of feelings and helped to control them. Besides, in the present study, the women made changes in their lifestyles. It has been stated in the literature that changes in lifestyles increase the sense of control, which helps feel healthier and promotes positive changes (25).

The women mentioned the unmet needs to join support groups and raise public awareness to decrease stigma over breast cancer patients in the society. When these needs are considered, it can be said that the psychoeducation might have had a limited role in improving social support. In Turkey, breast cancer survivors might be affected by stigma since cancer is still considered as a lethal disease (2). Therefore, it is not surprising that the women in this study wanted to be involved in social support groups, which involve women with similar problems. It is also clear in the literature that breast cancer survivors find support groups beneficial and want to join them (4, 26). In fact, support groups, in which self-disclosure and sharing worries with peers are promoted through normalizing experiences, understanding and acceptance, may play an important part in the development of PTG (27, 28). Another unmet need was negative perceptions of the society about cancer. The women wanted cancer-related anti-stigma campaigns to be organized. Results of studies on breast cancer patients in Turkey show that stigma is an important problem in cancer trajectory (2, 29, 30). In a society where people have a negative perception of cancer, it can be difficult for patients to complete their treatment and to express what they have experienced. Social stigma has been reported to be an important barrier to access to social support and adaptation to breast cancer (30). Therefore, the recommendations made by the women in the present study will play an important part in eliminating social stigma over breast cancer.

The women made some recommendations about the quality of the psychoeducational intervention. It is striking that the women asked for improvement about the frequency and duration of the sessions rather than its content. It has been emphasized in the literature that breast cancer patients have knowledge and support needs after treatment and health care systems may remain insufficient to fulfil these needs (4, 31). Similarly, in Turkey, there is a need for new follow-up care frameworks to improve the care of breast cancer survivors. Follow-up care usually involves clinical and radiological evaluations by physicians. For these reasons, psychosocial needs of breast cancer survivors are mostly not fulfilled during their follow-up (2). However, it has been noted in the literature that a good communication with health staff can be helpful. This communication should involve understanding patients' worries about their medical conditions and effective listening and should be based on trust (32). The psychoeducation sessions in this study provided this communication. In fact, the women mentioned their increased knowledge, opportunities to share their feeling and its effects on their emotional wellbeing and social life.

The women were satisfied with conduction of the psychoeducation sessions at home instead of a hospital-based intervention. Consistent with this finding, it has been reported in the literature that presenting to hospital for follow-ups reminds cancer and triggers fear of recurrence (2). It can be suggested that home-based psychoeducational

interventions can be used to offer other parts of survivorship care. Another recommendation made by the women is related to the word “sağkalan” in Turkish (It means survivor in English) in the booklet. In the present study, since the women did not want to remember cancer and did not want to live with cancer and since the word survivor reminds death, they did not approve of the term “survivor”. Similarly, in a study by Khan et al. (33) in the UK, most of the participants rejected being labelled a cancer survivor. In societies where there are breast cancer movements, these movements transformed the women with breast cancer from being a victim to being an activist demanding their rights. Consistent with the results of the current study, Klawiter (2004) reported that the women adopting breast cancer activism preferred the expression of “living with cancer” rather than “survivor” (34). An increase in campaigns against breast cancer and in activist movements among women in Turkey, which achieved mutual support between the women, have increased the women’s awareness of their personal strengths. These changes might have caused the women to define themselves as someone “saying hello to a new life” rather than a victim of cancer.

### Study limitations

The results of this study are specifically based on experiences of 32 breast cancer survivors who attended a home-based psychoeducational intervention. For this reason, they may not reflect experiences of breast cancer survivors offered different psychoeducational interventions.

The results of the present study provide new insights into experiences of breast cancer survivors who participated a psychoeducational intervention and provide guidance for attempts to improve survivorship care via psychoeducational interventions to nurses. The experiences of the survivors show that the psychoeducation supported PTG. Psychoeducational interventions should be continuously offered to provide psychosocial support for breast cancer survivors and to provoke PTG. Besides, the results of the study also suggest that psychoeducation in further studies needs to be restructured to involve social support. In addition, nurses and other health professionals should be aware of the effect of stigma and should conduct anti-stigma campaigns to change public perceptions of cancer.

**Ethics Committee Approval:** Ethics committee approval was received for this study from the Ethics Committee of Dokuz Eylül University School of Medicine (2011/04-04).

**Informed Consent:** Written informed consent was obtained from patient who participated in this study.

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